



BRAIN CANADA

A Submission on Bill C-277 An Act to establish a national strategy on brain injuries to the House of Commons Standing Committee on Health

August 2024

Improving quality of life for people with brain injury in Canada through research and services

Submitted by:

Anneliese Poetz, PhD

Senior Program Manager, Knowledge Mobilization (for Social Innovation)
Brain Canada Foundation

Viviane Poupon, PhD

President & CEO
Brain Canada Foundation



From left to right:
Nathalie B. Morin,
Stéphane Rouleau,
Nicole Hagley, and
Peter Kyriakides, all
brain injury survivors.

Summary

It is estimated that approximately 165,000 people per year experience a traumatic brain injury (TBI) in Canada. By 2031, TBI is projected to be among the most common neurological conditions affecting Canadians.

Because of the high numbers of people living with TBI, contrasted with the lack of resources to match the demand for services, people with brain injury are at a high risk of missing a critical window of opportunity for recovery. Brain injury affects every aspect of life. The negative consequences could be reduced if immediate and effective treatment options were available and accessed.

Through a recent extensive stakeholder consultation process, Brain Canada identified 55 unique needs related to brain injury in Canada. This alone speaks to the overwhelming number of gaps that could be addressed through a national strategy. Throughout our interview phase, we learned that brain injuries require immediate care; yet the services available for recovery from brain injuries are few, and wait lists are long. During this time, the brain injured person may be unable to work, relying on interrelated systems of disability supports and other financial aid, health care, private insurance, and sometimes the legal system. Some have friends or family to assist them, many do not. There are many inequities that become magnified through the reality of brain injury:

- funding for TBI research and outpatient services disproportionate to demand;
- long wait lists for assessment, treatment, and rehabilitation services lead to detrimental delays;
- variability in service availability and coverage across different provinces and territories;

Brain Canada's role in the ecosystem is to accelerate, amplify, and fund brain research and knowledge mobilization projects, and by providing researchers with this funding for addressing gaps in brain injury, we are helping to build much needed evidence-based solutions that will improve brain health in Canada. To date, three projects have been funded to address two of the top 10 priorities in TBI. This is just the beginning; social innovation requires a long-term view, with implementation and systems change as later stages. However, we can't do it alone; research and services must go hand in hand. Canadians require a national strategy for brain injury to support the implementation of research evidence into practice and improve provincial and territorial decision making about resource allocation for outpatient services toward optimal recovery.

Background and Statistics

Social innovations are new solutions that have the intent and effect of equality, justice and empowerment¹, create value for society², and catalyze transformative changes (impacts) to improve organizations, communities, regions or systems³. The social innovation cycle is characterized by six stages beginning with prompts (stakeholder needs), proposals, prototypes, sustaining, scaling and systemic change⁴. Brain Canada recently conducted extensive stakeholder consultations to inform its first social innovation program on traumatic brain injury (TBI) funded in collaboration with Brain Changes Initiative; through 78 interviews, a prioritization survey voted on by 456 stakeholders to identify the most pressing needs, and 10 focus groups. Throughout the process, we heard about the overwhelming lack of resources for the field of traumatic brain injury in contrast with a growing number of brain injuries. Lifetime medical care costs for brain injury are estimated at \$85,000 for concussion (mild TBI), \$941,000 for moderate TBI, and \$3 million for severe TBI⁵.

The Basic Social Problem: Reducing the effects of Brain Injury

At the outset of this program, Brain Canada sought a better understanding about how to achieve the greatest impacts for people who have experienced brain injury. Brain Canada considers impact to have been achieved when people with brain injury recover to the fullest extent possible or by preventing brain injury altogether. A core category or 'basic social problem' arising from the data was *reducing the effects of brain injury*. By seeking to understand this 'basic social problem' more fully, it can inform future research programs undertaken by Brain Canada, and other initiatives by governments, community organizations and individuals to help meet stakeholders' needs for being able to reduce the effects of brain injury.

The Basic Social Process: Immediate access to the specialized care needed following brain injury

The analysis led to the identification of another type of core category called a 'basic social process' (BSP) that addresses the basic social problem. The basic social process identified was *immediate access to the specialized care needed following brain injury*. Individuals living with brain injury are motivated to return to their pre-injury life and career. They need immediate access to assessments, diagnostics, services and treatments that have been individualized for their unique symptoms. This can be accomplished in part by removing existing barriers which only serve to delay, worsen, and prevent people with brain injury from achieving the best recovery possible for their situation. Frontline workers also need to be able to provide the services and treatments their clients need, as soon as possible after brain injury and for as long as needed.

1 Anderson et al., (2014). Definition and Theory in Social Innovation. Master of Arts in Social Innovation, Danube University, Krems. P. 1-36.

2 Phills, J. A., Deiglmeier, K., & Miller, D. T. (2008). Rediscovering social innovation. Stanford Social Innovation Review, 6, pp. 34-43.

3 Source: <https://www.canada.ca/en/employment-social-development/programs/social-innovation-social-finance.html>

4 Murray, R., J. Caulier-Grice, G. Mulgan (2010). The Open Book of Social Innovation. The National Endowment for Science, Technology and the Arts (NESTA). Accessed July 3, 2024 from: <https://youngfoundation.org/wp-content/uploads/2012/10/The-Open-Book-of-Social-Innovation.pdf>

5 Hendrick, K. et al., (2023). Traumatic Brain Injury: A Lifelong Condition. Accessed August 9, 2024 from: <https://braininjurycanada.ca/wp-content/uploads/2023/07/TBI-Paper-English-July-19-2023.pdf>

Barriers to immediate access to specialized care include: government level resource allocation decisions that favour acute care at the expense of outpatient services, policies, service availability and quality, waiting lists for assessment and access to treatment and services, lack of information about rights and services, limitations of insurance contracts, financial constraints, environmental conditions including aspects of the physical environment⁶ and the social environment⁷, and individuals in positions of power to help (such as physicians and allied health care professionals) but who do not have the necessary understanding about brain injury to detect it early, nor avenues for referrals when brain injury is suspected. Other systemic barriers include legal, political, bureaucratic, and lack of coordination and communication among relevant organizations and professionals. By removing barriers, people with brain injury become able to achieve the best possible outcomes for their condition, and families/caregivers become better equipped to provide assistance and advocacy. To this end, facilitating immediate access to the specialized care needed following brain injury emerged as an overarching need that relates to all seven themes and 55 focus areas. Thus, the basic social problem of **reducing the effects of brain injury** is addressed by the basic social process **immediate access to the specialized care needed following brain injury**.

There is not enough resource allocation for publicly funded outpatient treatments and rehabilitation services following brain injury at the provincial/territorial level.

“At the Ministry level, they have no knowledge of brain injury, and it translates into lack of services and lack of funding. Taking down silos is expensive, but they’re paying for it now anyway with the revolving door of police, social and health services.” – Neuropsychologist

“The whole system needs to be changed. The provinces need to open up the services they’ll cover. If we don’t have private insurance to cover the rehab we need, we have to pay out of pocket. Even with insurance, there are delays in treatment. It’s very short sighted, because providing rehab services early will help us recover sooner and better, but without treatment it will cost more to the government in the long run.” – Brain Injury Survivor

Long waiting lists lead to poorer outcomes. Little investment in outpatient services has resulted in wait lists of 6 months to a year for an assessment and another 2 years for rehabilitation services. These long wait times result in symptoms that are more difficult to treat, and worse long-term outcomes.

“There is a 2 year waiting list. Without treatment, symptoms become chronic and much more difficult to treat.” – Dr. Alain Ptito, Neuropsychologist

⁶ Such as stop-start movement on public transportation, computer or phone screens, lights, sounds, smells, etc.

⁷ Isolation, mental health and emotional dysregulation issues due to brain injury, brain injury peer support groups, societal perceptions, etc.

Individuals with brain injury desperately want to return to their pre-injury lives and careers, but their recovery is limited based on timely access to treatment.

Inequities in access to treatment. Access to treatment is dependent upon the cause of the injury, and whether there is health, home, work or auto insurance that can cover some of the costs. For services that are ineligible through private insurance, many find that the rehabilitation they need is also not covered by their provincial government.

"You know what would benefit the patient, but your hands are tied because there isn't funding or access for it." – Dr. Chantal Vaidyanath, Physiatrist

"There are too many layers, too much red tape to get through, it's embarrassing. There are so many funding systems and nobody's talking to each other. Care is frontloaded and funding goes to acute care but once you're out of the hospital, it's abysmal, but that's where it's important. The system is worn down to a nub." – Kyle Whaley, Physiotherapist

For many, the only option is to pay out of pocket, and since many cannot, they go without treatment.

"All my money goes to living expenses, so I have to go without all the treatment I need."
– Kristin Baetz, Brain Injury Survivor

Inequities across Provinces and Territories. Each province and territory makes its own decisions related to resource allocation for acute care and outpatient services, and there is variability across the country.

"Everything comes down to funding, access, and time. All of these changes are political."
– Alexander M. Voudouris, Lawyer

A national strategy could catalyze changes in funding allocation decisions for health care specific to brain injury, at the provincial/territorial level but it must be informed by evidence. We need reliable, comprehensive data for Governments to make informed decision-making. By providing researchers with funding in brain injury, as well as stakeholder informed direction on where the greatest impacts can be achieved, we can build much needed evidence-based solutions that will improve brain health in Canada.

Recommendations

We express our support for all items outlined in Bill C-277, and propose an additional recommendation to support the rehabilitation and recovery of individuals following brain injury:

- Evaluate government allocation of health care funding for acute care and outpatient services, toward more equitable and immediate access to quality no cost treatments and services for the best possible recovery from brain injury.

Conclusion

A national strategy on brain injury will inform funding decisions made by all levels of government to increase the availability of outpatient rehabilitation services. There is an urgency for immediate and publicly supported rehabilitation services for optimal recovery from brain injury.

About your organization

Brain Canada Foundation (Brain Canada) is a national registered charity established in 1998. Our mission is to accelerate, amplify, and fund brain research across Canada. By supporting innovative studies and collaboration, we are taking important steps towards understanding and treating neurological conditions, ultimately improving quality of life for all people in Canada.

References

Poetz, A. (2024-08-07). Stakeholder Engagement Report: Social Innovation Program for Traumatic Brain Injury. Brain Canada Foundation. *Unpublished manuscript*.